

Original Research Article

Family presence during resuscitation: patient and family members' preferences and attitudes

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ABSTRACT

Background: This literature review presents a review of the available studies into family presence during resuscitation (FPDR) in the context of emergency department and critical care unit from the point of view of patients and family members. This literature review provides the background for understanding the debate about FPDR. The paper examines the state of current research on the topic and points out gaps in existing literature.

Methods: A comprehensive search of OVID Nursing, Web of Science (Web of Knowledge), Elsevier, ProQuest and Google Scholar electronic search engine. Thematic analysis was used to extract themes from the 25 studies reviewed (quantitative, qualitative and mixed-methods studies), resulted in five major themes and five minor themes.

Results: Five major themes from this literature review were: (1) patient and family members' preferences; (2) perceived benefits of family presence during resuscitation; (3) perceiving family presence as a right; (4) the importance of a family facilitator; and (5) the involvement of decision making.

Conclusions: This literature review has established the potentials of family presence during resuscitation to improve patient and family-centred care by helping and providing family members to manage and to adjust during traumatic circumstances.

Keywords: Attitudes, Family members, Family presence, Patient, Preferences, Resuscitation

INTRODUCTION

Family presence during resuscitation (FPDR) is defined as the presence of relatives in the area of patient care where the family members can have a visual or physical contact with the patient during resuscitation and invasive procedures.¹ The first documented evidence of family presence was in 1982 at the Foote Hospital in America where family members requested permission to be present in the resuscitation room. Following this occurrence, in 1985, Doyle et al conducted a survey among 55 family members and 21 health care providers in the emergency department at the Foote Hospital.²

From their study, 71% (15) of the staff endorsed the practice of FPDR and most of family members (94%)

believed that their presence would be beneficial for the patient and therefore their adjustment to death was easier.

Since then, the practice of allowing the family members to be present at the bedside has been studied globally. Many researchers had published their research findings in this issue from the point of view of health care providers.

However, there have been approximately 25 studies conducted around the world which were putting patient and family members as the focus of the research. These studies were exploring and describing their opinions, attitudes, and experience about the option of giving relatives an opportunity to be present at the bedside during cardiopulmonary resuscitation. Furthermore, numerous professional organisations have issued a

position statement regarding the option of family presence. The American Heart Association recommends an option of FPDR in their guidelines on cardiopulmonary resuscitation and emergency cardiovascular care.³ The Emergency Nurses Association also offers an option for FPDR.¹ In addition, the American Association Critical-Care Nurses updated a practice alert for supporting family members to be present at the bedside during resuscitation.⁴ The European Resuscitation Council also proposed the option of allowing family members to be present during resuscitation in their new guidelines.⁵ There were no published literature review about patient and family members' preferences and attitudes towards FPDR. Accordingly, this review of the literature will be used to inform debate surrounding FPDR which focuses on patient and family members. This literature review aims to present a review of the available studies into FPDR in the context of emergency department and critical care unit. This literature review provides the background for understanding the debate about FPDR. This review will support the need for investigation of the attitudes of Indonesian's doctors and nurses who work in the emergency department and critical care unit.

METHODS

A comprehensive search of OVID Nursing, Web of Science (Web of Knowledge), Elsevier, ProQuest and Google Scholar electronic search engine finally identified 25 articles for literature review. Key search terms entered in the electronic search included; family presence, resuscitation, patient, family members, relatives, and resuscitation. The articles reviewed were published in English examining FPDR in the context of emergency nursing practice and critical care unit; therefore, any non-English articles were excluded. No restrictions on the research design of the articles were made.

Screening and data extraction

The search strategy firstly yielded 222 peer reviewed journals. The author assessed electronically the titles and abstracts using preliminary inclusion criteria. Four inclusion criteria guided the retrieval strategy: (1) the report of an original research study; (2) a study focus on family presence during resuscitation; (3) the study conducted in the context of emergency department and critical care practice; and (4) the study concentrate on patient and family members or relatives. A number of articles that were not research-based were excluded. After exclusion, 58 articles were identified. Each article was reviewed against the inclusion criteria and 25 articles remained post review of inclusion criteria and underwent a full review. The process of articles retrieval was described in Figure 1.

Fifteen (60%) of the studies employed descriptive quantitative approach, nine (36%) of them utilised qualitative methodology and one study (4%) was a

mixed-method research. The reviewed studies researched on patient and family members' attitudes and preferences regarding FPDR in 8 different countries surrounding the United States of America (n = 12), Europe (n = 8), Australia (n = 2) and Asia (n = 3). The summary of articles which were included in this review of the literature was listed in the table based on the methodology, sampling and sample, major findings, research limitations and the implications for review.

RESULTS

Four major themes were identified following analysis of the reviewed studies. The author performed a manual thematic analysis to obtain five major themes and five minor themes from articles reviewed. Each article was read several times, analysed and major themes extracted. Polit and Beck stated that 'A thematic analysis essentially involves detecting patterns and regularities, as well as inconsistencies'.⁶ Five major themes and five minor themes were discovered through the review of each study in an attempt to answer the review question. Subsequently, five major themes from this literature review were: (1) patient and family members' preferences; (2) perceived benefits of family presence during resuscitation; (3) perceiving family presence as a right; (4) the importance of a family facilitator; and (5) the involvement of decision making.

Theme 1: patient and family members' preferences

The first major theme emerged in this literature review was patient and family members' preferences and attitudes regarding family presence during resuscitation. Doyle et al published their first research concerning the practice of family presence during resuscitation in the United States of America.² From this descriptive quantitative study, they discovered that out of 55 family members, 94% of them stated they would want to be present during resuscitation of their loved ones. Correspondingly, Grice et al descriptive quantitative study aimed to describe the attitudes of staff, patients and relatives to witnessed resuscitation in an adult intensive care unit in the United Kingdom.⁷ From this study, they revealed that 29% of patients and 47% of family members desired to be together during cardiopulmonary resuscitation

Pasquale used the Spielberger State-Trait Anxiety Inventory (S-STAI) and a Revised Critical Care Family Wellbeing test (R-CCFNI) to explore the impact on participants who were either present or not present during trauma resuscitation.⁸ Interestingly, family members who were present during resuscitation scored better than those who were not present suggesting that they experienced less anxiety, greater satisfaction and better family well-being.⁸ Mazer et al also reported from their descriptive study that there were 49.3% of family members which were randomly selected to participate in a telephone survey desired to be present during resuscitation.⁹ In

Europe, there were small number of family members who wanted to be present during resuscitation of their loved ones, both from the study conducted by Barrat and Wallis and Azouly et al.^{10,11} They were 33.4% (18 out of 544 respondents) and 31% (24 out of 78 respondents) respectively. In contrast, some researchers from the United States of America found out that the number of relatives who preferred to be present at the bedside during resuscitation of their family member was bigger than that of in Europe.¹²⁻¹⁵

Furthermore, there were three articles from the patient's point of view regarding their preferences on family presence during resuscitation. Two studies were conducted in the United State of America by Eichhorn et al and Benjamin et al; and four years later, a United Kingdom researcher, McMahon-Parkes et al done their descriptive qualitative study in 2008.¹⁶⁻¹⁸ All participants in both Eichhorn et al and McMahon-Parkes et al qualitative studies supported the practice of having loved ones present during resuscitation.^{16,18} One resuscitated survivor stated: I would feel safer that someone [family members] was with me.¹⁸

Moreover, Benjamin et al conducted a descriptive quantitative study aimed to determine patients' preferences regarding family presence during their own resuscitation.¹⁷ 200 out of 266 respondents participated in this survey. 72% of the respondents wanted a family member present during resuscitation. Leung and Chow also reported in their cross sectional survey study that 55 out of 69 (79%) family members supported the family presence during resuscitation practice.¹⁹

There also appeared to be a growing support for family presence among the general public with 73.1% of the public supporting witnessed resuscitation.²⁰ This study surveyed members of the general public waiting in an emergency department waiting room for treatment and compared those results with data from a survey of medical staff and their attitudes towards family presence. Generally, most participants in these seven descriptive qualitative studies also indicated their strong preferences to be present during their loved ones' resuscitation. They believed that their presence was helpful for them not only during a psycho physiological crisis and but also would comfort their loved ones.²¹⁻²⁵

Theme 2: perceived benefits of family presence during resuscitation

The second main theme appeared was perceived advantages of family presence during cardiopulmonary resuscitation. There were five minor themes included in this first theme, they were; emotional support, patient-family connectedness, knowing and understanding, helping bereavement, advocacy and active participation. The following section presents each of five minor themes respectively.

Emotional support

In the descriptive study conducted by Meyers et al in the emergency department of a 940-bed, university affiliated, regional, level-I trauma centre in America, 80% (77 out of 96) of the respondents thought that family presence is important to meet the family members' and patients' both emotional and spiritual needs.²⁶ Correspondingly, being present at the bedside during resuscitation was seen by twenty-four per cent of relatives in Grice et al⁷ study as the way to provide support. Family members could have supporting the patient, expressing their love and making their peace.^{22,24,27,28} Emotional connectedness also appeared as major theme in the qualitative study done by Leung and Chow in Hong Kong.¹⁹ This interpretive phenomenology study was aimed to describe experience of family members whose relatives survived the resuscitation. Although none of participants in their study was present, the majority of relatives indicated a strong preference to be present if given the option. One of the reason was they felt emotionally connected with the patient. To be able to see and touch a critically ill family member was an important experience, as these establish physical and emotional connection. Moreover, from the patients' point of view, most participants in McMahon-Parkes et al qualitative study believed that they would or had personally benefited from the support and encouragement provided by family members during resuscitation.¹⁸

Patient-family connectedness

Patient-family member connectedness and bonding were described as powerful needs for the relatives, especially during a critical moment. Weslien et al interviewed convenience sample of nineteen participants out of forty-one family members from two hospitals in Sweden.²² They discovered one theme out of four themes, to be caring for the good of oneself and others. Family members in their study described this as a feeling of relief, trust and protection. Emotional connectedness between patient and their relatives also emerged in these studies.⁸ In addition, from the patient's perspective, Eichorn et al also revealed similar things that of from family members' point of view.¹⁶ In their study, they used the Family Presence Patient Interview Guide (FPPIG) to interview nine purposive samples of patients in the emergency department of a university affiliated, regional, level 1 trauma centre in the USA. From this interview, they found out one theme on maintaining patient-family connectedness. The participants who had undergone resuscitation noted that family presence helped them connected to the family unit. One participant stated: We are always together...we do everything together. Any time we have problems, we go through [them] together.¹⁶

The similarity of preferences and attitudes between patient and relatives on the benefit of family presence has shown that this practice should be implemented in the setting of emergency and critical care area of practice.

Knowing and understanding

Grice et al surveyed 55 patients and next of kin in the adult intensive care unit at a large hospital in the UK to describe their attitudes to witnessed resuscitation.⁷ They found out that 24% of patients and 47% of family members wanted to present during resuscitation. Most reason was that it would provide support and to see that everything was done for the patient. Similar reason also emerged in Ong et al descriptive study in Singapore.²⁰ Respondents from their study believed that the most common benefits of witnessed resuscitation was that family presence could give assurance to relatives that the resuscitation team was already give the best effort to save their loved ones' life. Some researchers who conducted descriptive qualitative study also found similar things. Observing the resuscitation team perform cardiopulmonary resuscitation on their loved ones would assist relatives understand the reality of their family member's critical situation.^{18,21,22,24,25}

Helping bereavement

The first published research regarding family presence during resuscitation conducted by Doyle et al in 500-bed urban community hospital in the USA.² Fifty-five family members participated in their mailed survey; 76% of family members believed that their adjustment to their loved ones' death was easier if they were allowed to be present during resuscitation. Ten years later, Robinson et al, a UK researcher, conducted a randomised control trial (RCT) using five standardised questionnaires; The Impact of Events Scale (IES), The Hospital Anxiety and Depression (HAD), The Beck Anxiety Inventory (BAI), The Texas Inventory of Grief (TRIG), and The Beck Depression Inventory (BDI).¹³ They reported from their study that in the witnessed resuscitation group, most of relatives felt their grief had been eased. In addition, being present at the bedside during resuscitation indicated that there were no reported adverse psychological effects among the relatives who witnessed resuscitation. Correspondingly, Meyers et al also reported their results from their study in the United States of America.¹² 68% of family members who participated in their telephone survey believed that their presence might have helped their sorrow following the death of their loved ones.

In Asia, Ong et al conducted study which aimed to compare the attitudes of the public attending at a local emergency department and the medical staff towards family presence during resuscitation.²⁰ From the total of 145 family members which were surveyed by Ong et al²⁰ in Singapore, 68.8% (n=100) of the respondents felt that being permitted into the resuscitation room would help in their grieving process. Additionally, the reason why a family facilitator is needed during resuscitation was it would decrease a risk of medico legal litigate as indicated from Leung and Chow study in Hong Kong.¹⁹

Advocacy and active participation

The literature revealed that being present during resuscitation would facilitate family members to be an active participation and an advocate for their loved ones. A study in the United States of America showed that families in the study viewed themselves as active participants in the patients' care process²⁶. Particularly, in a qualitative study involving family members, Weslien et al²² found that their presence would be valuable for health-care professionals, themselves or the patient. They could inform health-care professional important information regarding the patient's condition.

I can inform (the staff) about something that is not written in the medical record. It is not easy (for the staff) to read that (medical record) in a second. They read that he had undergone coronary bypass. I could inform them that four blood vessels were replaced and that was important information. Therefore, I wanted to be there (in the resuscitation room) if any questions should be asked.²²

In later research, McMahon-Parkes et al interviewed patients about their views and preferences regarding family members during resuscitation.¹⁸ These resuscitation survivors explained that as their ability to interpret information or exercise autonomous judgements would be compromised, they would prefer family members to help by representing their interests.

Theme 3: perceived family presence as a right

The next major theme emerged in this literature review was perceived family presence as a right. A descriptive qualitative research done by Eichorn et al in the emergency department of a university-affiliated hospital in USA was aimed to describe the experiences of the patients towards family presence during resuscitation.¹⁶ They used a semi structured, open-ended questions developed by them to interview nine patients. Participants in their study indicated that having family members at the bedside during resuscitation was their right. One patient voiced:

If it is going to help me go through the procedure better, I think I should have the option of whether he is there or not; if it is going to comfort me and somehow help things go easier.¹⁶

All participants in a mixed-method study conducted by McGahey-Oakland et al indicated that being present with their child was a definite right.²⁹ This study was done in a large paediatric tertiary hospital in the United State of America and aimed to describe experiences of family members whose children underwent resuscitation. One mother in their study said:

If you are the parent, you have every right to be with your child...nothing should be hidden from you, especially if it's a life-threatening situation.²⁹

From those two different perspectives, it was clear that both patient and relatives understanding family presence as their right.

Theme 4: The importance of a family facilitator

The fourth main theme emerged in this review of literature was the importance of a family facilitator during resuscitation. Family facilitator is a health care staff, either nurse or doctor, who will explain the procedure to family members at the bedside during resuscitation. The importance of a family facilitator emerged as a major theme in the Morse and Pooler study.²⁷ Locating at the emergency department of Level I trauma centre in the USA, this qualitative ethology research used a secondary analysis from 33 videotapes which were analysed and coded on behaviours and verbal interactions. Nurses' interaction with the patient and relatives depended on the situation between patient and family. As for example, when families learning to endure, nurse informs about patients' condition and encourages them learning to endure.

In later research, family members in the Wagner qualitative study also wanted someone explaining the situation happened during the process of resuscitation.²¹ Specifically, the parents who participated in Maxton phenomenology research stated that the best support must be provided by the experienced clinical nurses during resuscitation.²⁴ Consistently, Harvey and Pattinson conducted a qualitative study in the UK which aimed to explore fathers' experiences of the resuscitation of their baby at delivery.²⁵ From the interview, they discovered that a family facilitator during resuscitation was essential for the family members. The fathers indicated that a family facilitator would give important information on their child's condition. Resuscitated survivors in the McMahon-Parkes et al qualitative study also shared similar idea regarding the importance of a family facilitator during resuscitation.¹⁸ This study designed to explore the views and preferences of resuscitation survivors and those admitted as emergency cases, as to whether family members should be present at their resuscitation. In this study, participants believed that health care professionals should facilitate the presence of loved ones as appropriate.

Theme 5: The involvement of decision making

The last major theme emerged in this review was decision making involvement. Out of twenty-five studies reviewed, there were only two studies indicated this fifth theme. Boie et al conducted a survey in the waiting area of emergency department from an urban, teaching hospital and obtained 400 respondents.¹⁴ Most of parents their descriptive quantitative study wanted to participate

in the decision about their presence during their children's resuscitation. In addition, from the telephone survey conducted by Mazer et al, the respondents in their study shared similar percentage on who should have the authority in making decision of the family's presence.⁹ Of the 408 respondents, 43% of them believed that the doctors should have the most authority in making decisions about witnessed resuscitation. They thought that the physicians were the person who know and understand exactly the patient's condition. Correspondingly, 40% of the relatives considered that the patient should have the authority in making this decision.

DISCUSSION

Reviewing international studies help us to develop a broader understanding of issues and problems faced on a daily basis in emergency clinical practice. From a seminal research done by Doyle et al study indicated that there was a relatives' strong preference for family presence during resuscitation.² There were also a growing number of studies undertaken by researchers in some countries relating to family presence during resuscitation from health care professionals perspectives. They revealed that health care professionals differed in their attitudes and views in the practice of family presence during resuscitation. Many respected professional organisations also support the option of family presence during resuscitation with appropriate health care professionals' assistance.^{1,3-5}

Despite of these recommendations and the discrepancy of health care professionals' attitudes and preferences, it is also important to understand from other perspectives, such as patients itself and their relatives to this practice. From a review of literature on patient and family members' attitudes and preferences regarding the practice of allowing family to be present at the bedside during resuscitation, there were massive supports from both of them. Most of them wanted to be together during a critical situation like cardiopulmonary resuscitation. They believed that there were more benefits than the risks. However, they saw a lack of support from health care professionals relating their needs of a family facilitator. They assumed that a staff member of the resuscitation team would help them understand the procedure given to the patient and its outcome.

Seeing both patients and relatives' views and preferences, health care professionals have to accommodate their needs during a critical time. Providing a staff member, for example an experienced clinical nurse, it would help the families understand and knowing that everything was done for the patient. Therefore, it is important to establish the role of a support person with appropriate training of crisis and bereavement management to accompanying the family's' presence. Understanding the patient as a member of family unit would help us providing a holistic care for the patient and family. For a long term, it would be benefited not only for the patient but for health

institution also. As it commonly believed that the patient's satisfaction would be benefited to minimise their length of stay.

As discovered in some studies that inviting family members in the resuscitation room would also give benefit to health care professional as it may also decrease the risks of medico legal litigation. Therefore, hospital policy and guidelines about family presence should be developed to facilitate the practice. This practice could be successfully implemented with support and clear guidelines from managers. In general, both patient and relatives believed that they themselves benefit from family presence during resuscitation in different ways. Therefore, health care professionals should consider this practice to be implemented in order to meet the need of both patients and family members.

CONCLUSION

This literature review has established the potentials of family presence during resuscitation to improve patient and family-centred care by helping and providing family members to manage and adjust to traumatic circumstances. Multidisciplinary teams consisting of physicians, nurses, and other health care providers are needed to develop written policy and guidelines. The improvement of body of knowledge is also seen as a good method to build greater understanding between health care professionals towards family presence during resuscitation. While published data internationally assists in understanding family presence, the disparities in societal structures, health care systems, culturally and linguistically diverse populations emphasises the importance of further research on family presence during resuscitation, especially in the Indonesian background.

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